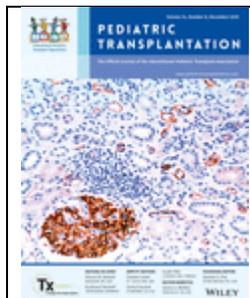


# Planning for the future of a pediatric kidney transplant recipient with special needs: A parent's perspective

By Maedi Tanham Carney



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Dear Friends & Family,

In October 2019 I was asked to write an article on planning for the future of a pediatric kidney transplant recipient with special needs: A parent's perspective by Ellie's nephrologists at Children's Hospital. It was accepted and published by The International Pediatric Transplant Association (IPTA) – The Transplant Society November 5th, 2020.

## **FORWARD**

Dearest medical professionals,

From the bottom of my heart, I would like to thank each one of you for the work you do for children with special needs specifically ones that need transplants. When I was pregnant with my first child, I could not wait to see a beautiful baby. Ellie was beautiful and being born with OFDS type1; I had a baby that was truly special. Her life road map and our journey did not have a manual and as it turned out we created one which was unique and only written for my daughter. Ellie could not be where she is today without the brilliant, kind, and wonderful medical professionals we dealt with at Children's Hospital in Washington DC.



The day of Ellie's birth was a planned cesarean birth. The entire family knew the date and we all waited with anticipation. Once Ellie was born, we heard everyone saying something wasn't right. Six hours later, I met one of the most important physicians in our lives, Ellie's geneticist who explained that my daughter was born with OFDS type1. She further explained that there would be many complications including a 50% risk of intellectual disability, kidney dysfunction issues

that most likely would end with a need for a transplant, and many other complications.

I will never forget that day and I appreciated how gentle the delivery of this news was by this incredible woman. Since that day, my life took a 180-degree turn. I took my baby home and spent the next twenty-four years at Children's Hospital. We left kicking and screaming as we never wanted to leave this group of brilliant and kind medical professionals.

Transition of care to adult is very difficult for families like mine that have been vulnerable and dependent on a pediatric team for as many years as we were. We were so intensely grateful for the kind guidance and careful education by our pediatric team. I trusted them and mostly, I trusted Ellie's geneticist as she led us to all the necessary medical professionals necessary in Ellie's life.

We remember with gratitude how communication was when things did not go as planned. During Ellie's first operation at 8 months, she crashed when they were extubating her. Ellie's surgeon was so soft spoken when he explained the ordeal. This surgeon did many more surgeries on Ellie and through the years, we had some great laughs. I even ran into him at a basketball game at his son's school and we shared a beautiful hug. It was always gut wrenching watching the nurses give Ellie the pink juice to relax before the IV and then they took her away for another operation. Ellie and I bonded with many different teams. In fact, we did laboratories and ultrasounds so often, and we even had a favorite ultra-sonographer and radiologist. It was not only the medical team that we worked with intensely.

Ellie had a developmental team, a physical and occupational team, a psychiatrist, clinical neuropsychologist, and an educational consultant who helped guide us through the school systems. It was so important to listen to all the professionals and let them guide us on Ellie's journey. Ellie was a busy baby and girl with many therapies, school, tutors, medical appointments, and surgeries.

Eventually our primary care changed from genetics to nephrology at Children's Hospital as she went through two kidney transplants, dialysis, and a few surgeons. It was exhausting, exhilarating, and devastating at times. Ellie's primary nephrologist had a tremendous amount of love and empathy within her despite her small stature. We truly became family and the entire team treated us with the same kindness portrayed in their leader. To this day, I can call or email her with a question on Ellie and she can share what I need.

Because of the nephrology team, Ellie was nominated to Make a Wish where she met Alex Ovechkin, the Washington Capitals star player. This was huge for Ellie and words cannot express the magnitude of this opportunity created by the nephrology team!

In the remaining sections of my article, I summarize my own personal experiences based on my years of planning for my daughter and setting up a business M&L Special Needs Planning, LLC and a non-profit Integrated Living Opportunities (ILO). All programs I am referring to only apply for people residing in the United States.

If you want to read the full article please email: [info@specialneedsplanning.net](mailto:info@specialneedsplanning.net).

# WILEY

This article can be found in its entirety on the Wiley Online Library <https://wileyonlinelibrary.com/> (search for *Carney, Maedi Tanham*):

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In 2014 I founded Integrated Living Opportunities to support the transition of young adults with disabilities to independent living.

My daughter, Ellie, was born with OFDS Type 1 and intellectual disabilities resulting in years of medical challenges. I worried about her future, especially as I aged, and knew that helping her become independent was part of the solution to her long-term livelihood.

ILO has helped build a community of support allowing her to successfully take care of herself without being vulnerable, lonely, or isolated.



*Ellie Today*